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Olivia Carpinello
Bridget Collins
Jennifer Covino
Daniel Fischer
Angelica Santos

See next page for additional authors

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Emergency and Scheduled Respite Care for Caregivers of Persons with Dementia: a Proposed Program

Carpinello, O.1; Collins, B.1; Covino, J.1; Fischer, D.1; Santos, A.1; Schoppel, K.1; Tadevosyan, A.1; Pendlebury, W., MD1; Martinez, L., RN2

1University of Vermont College of Medicine, Burlington, VT
2Visiting Nurse Association of Chittenden and Grand Isle Counties, VT

INTRODUCTION

Respite care is defined as providing the primary caregiver with relief or a reprieve from care commitments on a short-term or emergency basis. (cite 1) Despite a demonstrated interest (cite 2) in and need for respite care programs, our research has shown that scarce resources exist via a statewide dementia respite program administered by Vermont’s five Area Agencies on Aging (cite 3). Grants are small and many agencies do not fall within the eligibility requirements. In FY2010, only 290 families across the state met eligibility requirements (physicians’ diagnosis of dementia, income less than 300% of poverty line, unpaid caregiver, primary residence in VT) and were awarded limited funding for the provision of outside care (up to $750.00 each). For many of these families, this money is typically used to provide substitute care when the primary caregiver is not available. To date, there is no true emergency respite program in place for caregivers. This has placed a strain on families and day facilities, particularly when situations arise in which a caregiver is unable to pick up their family member due to an emergency situation. Our goal was to demonstrate the feasibility of a respite program to address this need.

METHODS

We began with a literature review and discussions with key agencies involved in the well-being of patients with dementia and their caregivers. These agencies included: The Visiting Nursing Association (VNA), Dept. of Disabilities, Aging and Independent Living (DAI), Vermont Chapter of Alzheimer’s Association, and the Vermont Area Agencies on Aging. Based on the input of existing community agencies, we drafted a program proposal for emergency and scheduled respite. Recognizing the paucity of funding sources as a chief limitation to current models, we developed a survey to assess the feasibility of a volunteer-based program. An electronic survey was sent via Survey Monkey to the volunteer pool at Fletcher Allen, members of the UVM community; AARP; and the United Way of Chittenden County, which includes the VNA. Based on our proposed program, and suggested community and financial resources that were not identified in our efforts.

RESULTS

The results from our survey demonstrate feasibility for a volunteer-based program. Of 95 responses to our survey, 71 individuals responded that they would be willing to volunteer. Within that group, 42 individuals were willing to volunteer with expenses paid and an additional 29 were willing to participate if provided a nominal fee in addition to their expenses (Table 1).

Additionally, we surveyed willingness to participate in a training program and background check (100%), interest in coverage of emergency and scheduled respite care (graph 1), timing of care (chart 1), regular commitments (chart 2), and donated hours (graph 2).

PROPOSED PROGRAM

Based on our results and investigations into local resources we would propose the following program and community partners:

Model
- Provision of service: < 72 hours for on-call emergency care or scheduled respite
- Program Administration by the Visiting Nurse Association of Chittenden and Grand Isle Counties
- Utilization of community volunteers
- Background Checks
- Training Program
- Reimbusement of out-of-pocket expenses
- Specialized care

Budget
- Our proposed budget includes the costs of annual administrative oversight (VNA), training (ElderWise), and estimated annual reimbursement costs for a pilot of 20 volunteers

COMMUNITY RESOURCES AND POTENTIAL FUNDING

Potential Community Partners:
- Administration: Visiting Nurse Association of Chittenden and Grand Isle Counties
- Training:
  - ElderWise system of Caregiving: adaptation of current 70 hour curriculum geared to non-medical caregivers.
  - Development of standardized reporting and medication forms for consistent volunteer documentation and reporting to families.
- Alzheimer’s Association: classroom and online training

DISCUSSION

The results from our survey demonstrate feasibility for a volunteer-based program. Of 95 responses to our survey, 71 individuals responded that they would be willing to volunteer. Within that group, 42 individuals were willing to volunteer with expenses paid and an additional 29 were willing to participate if provided a nominal fee in addition to their expenses (Table 1).

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CONCLUSION

Previous research has demonstrated a need for additional resources for caregivers of patients with dementia. Our group has demonstrated the feasibility of a volunteer-based program for the provision of emergency and scheduled respite care. In addition, our group has identified potential community partners and fiscal resources that should be further pursued to bring this much needed service to the community at large.